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Bringing heads together

Peer support and positive thinking can help overcome the challenges of living with arthritis

LISA MELTON

For all you know, Mark Earp (right) could have been as big as David Beckham. A talented football player, clubs including Ajax Amsterdam were keen to hire him and negotiations were underway. But with the results of the medical examination all negotiations stalled. The X-rays revealed his knee joints were ravaged by arthritis, shattering his dreams of becoming a professional footballer.

The damage was not recent. When he was 8 years old, Earp was diagnosed with acute polyarthritis – a form of arthritis that affects all joints. Overnight, his existence was transformed – from a carefree, agile boy he now found walking painful and was often wheelchair-bound. It was a lonely time. “In those days nobody, even the doctors, knew quite what to do with us.” Fortunately, 4 years on, the disease remitted and Earp bounced back to become a skilled sportsman. Unfortunately, his joints had been irreversibly damaged.

The football club's rejection letter was a thunderbolt to Earp. It forced



him to acknowledge that the disease wasn't going away, that his only recourse was to adapt. Despite his aching knees, Mark went on to play football semi-professionally for several years. “I learnt to be a survivor. It was sheer will power and determination,” he recalls.

Learning about Arthritis Care, a UK-wide voluntary organization, proved to be a turning point. Not only was his thirst for information satisfied but, he also met other young people in a similar situation. The positive spin on his life was such that Earp set up a helpline in the Isle of Wight to act as a

local contact for Arthritis Care, UK. "I wanted to tell people that there is something for them to do, that you can have a better quality of life," he says.

Now 45, he is excited by his latest sporting ventures: Earp has set up cricket, football, sailing, swimming and riding teams for people with arthritis and other disabilities in the island. "We now know that it is far better to exercise than not at all. The idea is to keep the joints supple." People join the teams not just for the exercise. "It's as much about keeping fit as for social interest. Sport helps people feel part of a community," Earp enthuses.

Children with arthritis

Debbie Stone's son, 12, however, would rather not mention his illness to his friends. "It's been very tough for him," says the London-based mum of two. "I don't think anyone can begin to comprehend what it's like for an active child to have arthritis" (see box). Stone's son was only 10 years old when an odd rash – probably due to an infection – precipitated juvenile



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Jan Slaney

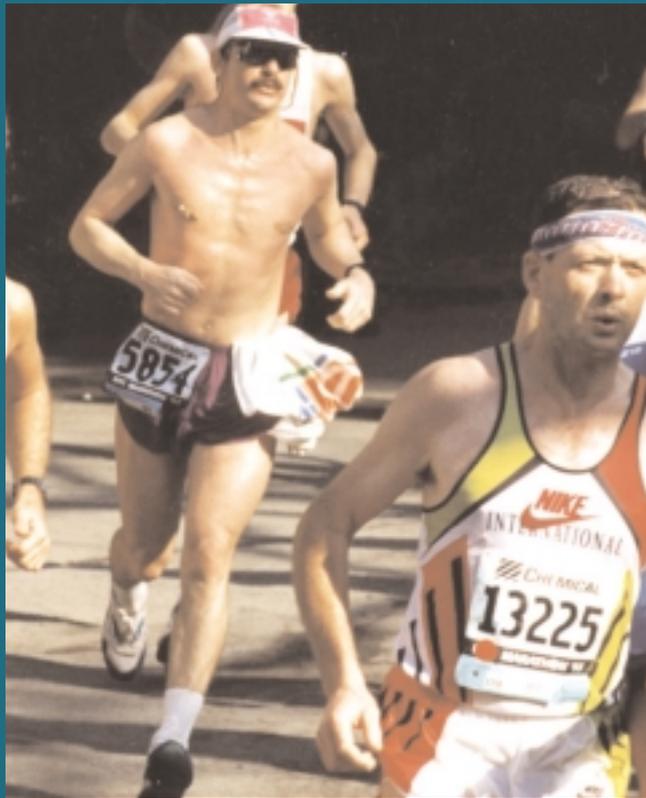
idiopathic arthritis, a rare form of arthritis affecting 1 in 1000 children. His limb joints seized up, his fingers tightened into a permanent grip and he could barely walk. The next 18 months turned into a nightmarish whirlwind of hospital stays, doctor's waiting rooms and physiotherapy. From being an athletic child, he was reduced to watching sport on television, missing school for most of that year.

"Initially, your main concern is that your child is taken care of," Stone concedes. Eventually, the child's pain and frustration and the time dedicated to their rehabilitation take their toll on family life. "It's very isolating as a parent. The hardest thing is not being able to find anybody else that is in a similar predicament," says Stone, who remembers feeling desperate and lost during the first few months following her son's diagnosis. A phone call to the Children's Chronic Arthritis Association changed all that. "They point you in the right direction by offering practical help and information. But perhaps what I valued most was the human contact and support, being able to talk to other parents with similar experiences," she reflects

The CCAA was originally set up in the UK to offer parents emotional support and to try to plug the information void that surrounds juvenile arthritis. "Knowledge of childhood arthritis is non-existent," comments an incredulous Stone. "People come up and recommend cod liver oil, others think it's like the stiffness they experience in the mornings. This is different! These children cannot walk unless they are taking drugs. Even general practitioners often fail to recognize the symptoms." Her son is now improving on treatment, and Stone has signed up to become a family area contact for CCAA.

Lifesaving tips

What everyone agrees is that an informed person is more likely to enjoy a better quality of life. Arthritis can affect everyone differently but the issues it throws up are similar – whether it's access to the right treatments, pain, immobility or even people's attitudes towards the disease. Jan Slaney who runs the 'Challenging Arthritis' course for Arthritis Care agrees that learning coping skills for



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Bob Welter

living with the everyday challenges of arthritis is vital. “They make a huge difference,” says Slaney, who at the age of 57 has endured the painful and debilitating consequences of osteoarthritis in her spine and hips for 30 years.

Slaney became deeply involved with Arthritis Care, the UK’s leading arthritis charity, after attending one of their 6-week self-management courses. She remembers thinking: “I could lead one of these courses,” and instantly volunteered. The leaders are always fully trained people who have arthritis themselves. Their own personal experience of living day-to-day with the condition helps breaks down any

communication barriers. Participants often feel more comfortable discussing the impact arthritis has on their lives with people like Slaney.

“People tend to arrive feeling depressed and fed up with pain and their arthritis. They are angry: why me?” says Slaney. “We teach them positive thinking and different ways around their difficulties. Our aim is to help people govern their disease rather than be governed by it.” The advice consists mostly of basic, down-to-earth tips from using shoe-horns and stair-lifts to the benefits of a walk-in shower and how to put on tights and stockings. “The daughter of an elderly lady came back in tears because she realized there was so much she could now do to help her mother,” enthuses Slaney.

Course attendees are also given basic scientific facts relating to their disease to help them understand where their aches and pains originate. How to communicate their feelings and needs to doctors also figures high on the agenda. Family situations are discussed too. “People often feel guilty not being able to do things with their children – not being able to kick the ball for example. We provide the encouragement they need to deal with these situations – that is the whole idea of the course,” says Slaney.

A swim a day

Today’s upbeat attitude is a far cry from the long-accepted myth that apart from buying a good pair of shoes and taking pills there was little that could be done. There are now multiple ways to manage pain through lifestyle changes, medications and surgery. New, safer drugs are available, and health-professionals are supporting alternative forms of therapy including massage, acupuncture and hydro-therapy pools.

Marathon runner and fitness instructor, Bob Welter, has set up a studio dedicated to bringing the benefits of exercise and meditation to people with arthritis. “Sometimes people hurt so much they stop going out. Exercise helps people get some of their life back. Our classes allow them to be more mobile, and what they achieve spills over into their everyday life,” says Welter who himself has osteoarthritis.

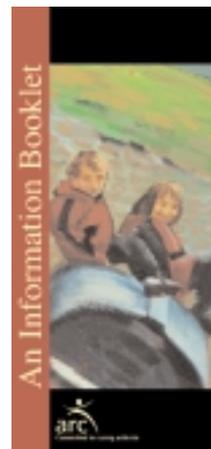
Welter, 47, who lives in Florida, US, only discovered he had osteoarthritis

New puppets on the block

Children often have tough questions. What’s wrong with Leslie Rosenbaum? Why does she sometimes come to school in a wheelchair? Can she still walk? Leslie was 5 years old when she was diagnosed with Juvenile Rheumatoid Arthritis. Leslie, who is now 10, explains to her classmates and friends that her type of arthritis affects many joints: knees, wrists, fingers and jaw. Sometimes when the disease flares up, she is in a lot of pain and that’s why, to cover long distances, she needs a wheelchair.

Leslie is no ordinary girl – she is a puppet. The people at Kids on the Block (KOTB) created the character to help children understand what it is like to have arthritis through the magic of a live puppet show. The script material was developed in conjunction with the Arthritis Foundation in consultation with numerous children who have juvenile arthritis.

The KOTB arthritis program covers specific issues such as the difference between juvenile forms of arthritis and osteoarthritis, what type of exercise Leslie needs, and misconceptions about the disease. “Because it’s lively and fun, kids feel safe to ask questions,” says Aric Darrow, a spokesperson for KOTB.



FURTHER INFORMATION
For more information on arthritis and arthritis support organizations see these web sites.

www.paremanifesto.org
www.arc.org.uk
www.arthritis.org
www.arthritiscare.org.uk

after a knee surgery intended to mend a torn ligament. As an athlete, he was devastated by the news. “At first I didn’t know where to turn to. When I found the Arthritis Foundation I discovered a wealth of very knowledgeable people who wanted to help. It’s a valuable resource – they help people take control of their disease.”

Welter’s fitness studio caters for people with disabilities, especially arthritis. There is an activity for every taste – from yoga and tai-chi to pilates and hydrotherapy. Amongst people with arthritis, aquatic workouts are an undisputed favorite – the warm water supports their joints, and the low-impact exercises encourage circulation and tone the muscles. Exercise can also help with depression, lifting mood and boosting a person’s self-esteem.

“Arthritis robs you of your ability to function. But if you have a positive mind set, you’ll find ways to get round it,” says Welter. “Attitude is everything and I’m not letting arthritis stop me.”

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